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Genetic Determinism or Genetic Discrimination?

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GENETIC DETERMINISM OR GENETIC DISCRIMINATION?

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"Anatomy is destiny."

Sigmund Freud†

"A man consists of some seven octillion (7×10^{27}) atoms, grouped in about ten trillion (10^{13}) cells."

Theodosius Dobzhansky‡

INTRODUCTION

The publication of Aldous Huxley's *Brave New World* in 1946 predated the discovery by James Watson and Francis Crick of deoxyribonucleic acid (DNA) by seven years.[1] Commentators continue to view the significance of advances in recombinant DNA (rDNA) technology through the

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In June, 1993, I participated in a Conference on Law and Biology in Squaw Valley, California, sponsored by the Gruter Institute for Law and Behavioral Research. A number of my ideas presented in this essay have been influenced and, indeed, shaped as a consequence of my participation in this Conference. In August, I had a research affiliation with the University of Queensland in Australia as a Visiting Professor where I continued to refine my ideas and my research and writing for this essay. I take the opportunity to thank Professor Geoffrey deQ. Walker, Dean of the Law Faculty, and Professor Carolyn Sappideen for their gracious hospitality and support during my stay. I also wish to acknowledge the research assistance of Patricia A. Kaufman.

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This article is dedicated to Professor Margaret A. Somerville in friendship and as an acknowledgment not only for her path breaking work in Law, Science, and Medicine, but for her compassion, courage, generosity of spirit, steadfast loyalty, and commitment to teaching the Song of Life *vivace* as an inspiration to all around her.

† XI THE STANDARD EDITION OF THE COMPLETE PSYCHOLOGICAL WORKS OF SIGMUND FREUD (James Strachey ed. & transl., 1910) 89; XIX 178 (1961).

‡ GENETICS OF THE EVOLUTIONARY PROCESS 1 (1970).

1. James Watson & Francis Crick, *Genetic Implications of the Structure of Deoxyribonucleic Acid*, 171 NATURE 964 (1953).

lens of Huxley's totalitarian society,[2] a genetic caste system made possible by genetic technology.[3] The alternative characterization of such technology as a grail to treat or heal inherited diseases is perhaps less alarming, but similarly fails to adequately describe the current state of technology both from the perspective of identifying specific genetic traits and developing gene therapy.[4] Nevertheless, in 1993, the fortieth anniversary of the discovery of the structure of DNA,[5] the Human Genome Initiative continues its mapping of the human genome.[6] The accelerated pace of mapping that began in the early 1970s[7] is expected to continue due to innovations in genome mapping and sequencing.[8]

The salutary effect of this technology and the ability to catalog and analyze the genotype of a particular individual create the potential for abuse of such information. Indeed, for some, the eugenics movement[9]

2. Kimberley Nobles, Note, *Birthright or Life Sentence: Controlling the Threat of Genetic Testing*, 65 S. CAL. L. REV. 2081 (1992). *See* GEORGE P. SMITH, II, THE NEW BIOLOGY: LAW, ETHICS AND BIOTECHNOLOGY (1989); GEORGE P. SMITH, II, GENETICS, ETHICS AND THE LAW (1981); George P. Smith, II, *Manipulating the Genetic Code: Jurisprudential Conundrums*, 64 GEO. L.J. 697 (1975).

3. Such rDNA advances include germ-cell or germ-line therapy, whereby genes within sperm or eggs are replaced or repaired to the effect that such modified genetic material is passed on to the next generation. OFFICE OF TECHNOLOGY ASSESSMENT, BIOLOGY, MEDICINE, AND THE BILL OF RIGHTS: SPECIAL REPORT 40 (Doc. No. OTA-CIT-371 U.S. Government Printing Office, Sept. 1988). In contrast, somatic cell therapy does not cause inherited or inheritable changes. It might provide, for instance, a means of replacing the defective gene in the bone marrow cells of a child affected by genetic immune deficiency. If successful, such therapy would "cure" the child but would have no effect on his or her own offspring. *Id.*; *see also The Aim is to Get Genes to Do the Work*, NEWSDAY, July 6, 1993, at 59. *See generally* D. NELKIN & L. TANCREDI, DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION (1989); Sir Gustav Nossal, Symposium, Introduction, HUMAN GENETIC INFORMATION: SCIENCE, LAW AND ETHICS (1990).

4. THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT (Daniel J. Kevles et al. eds., 1992). *See generally* George P. Smith, II, *Uncertainties on the Spiral Staircase: Metaethics and the New Biology*, 41 THE PHAROS 10 (1978).

5. *The Aim is to Get Genes to Do the Work*, *supra* note 3, at 59. *See also Changing your Genes*, THE ECONOMIST, Apr. 25, 1992, at 11; Leon Jaroff, *Making the Best of a Bad Gene*, TIME, Feb. 10, 1992, at 78.

6. *See* Carol Lee, Comment, *Creating a Genetic Underclass: The Potential for Genetic Discrimination by the Health Insurance Industry*, 13 PACE L. REV. 189, 195 (1993).

7. Clive Cookson, *The Men Who Would Play God*, THE FINANCIAL POST (Wkly. Ed.), Feb. 10, 1992, at S37.

8. Daniel Kevles & Leroy Hood, *The DeoxyriboNucleic Acid Test*, S.F. CHRONICLE, Dec. 5, 1992, (Section Z1), at 8.

9. "The basic idea of eugenics was to improve the human stock pool by increasing the number of supposedly desirable human beings ("positive" eugenics) and getting rid of undesirable ones ("negative" eugenics)." *Id.* In Nazi Germany, the eugenics movement rationalized policies of mass sterilization and ultimately the creation of death camps for the extermination of individuals deemed undesirable by virtue of ethnicity, religion, or sexual

still casts a shadow over the Human Genome Project. The risks of abuse engendered by the mapping of the human genome and emergent rDNA technology do not extend to social engineering and the development of a "superior" human, a process necessitating germ-line modification. Rather, the potential abuse may result from discrimination based on the dissemination of key information about the genotype of an individual—information revealing the risk factors inherent in that individual.[10] Genetic data is a particularly sensitive category of health care information.[11] Unlike information about a specific transient condition or illness, data pointing to a genetic disorder will affect, and may stigmatize, a person throughout his or her life.[12] The handling of genetic information by the state or its agents, therefore, implicates individual liberty interests derived from fundamental constitutional rights to equality and privacy.[13] In

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orientation. *Id.* Similarly, in the United States, many states enacted sterilization laws justified in large part by eugenic principles. *Id.* In California alone, 6,255 individuals were sterilized by 1929. *Id.* Most of these laws were overturned, however, by a decision of the United States Supreme Court in 1942. *Id.*; *see also* Skinner v. Oklahoma, 316 U.S. 535 (1942).

10. *See* Paul R. Billings et al., *Discrimination as a Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 479, 481 (1992). The findings of this study affirm the existence of discrimination against individuals who are completely asymptomatic, their only "abnormality" lies in their genotypes. *Id.* at 479. Indeed, it appears that genetic conditions are regarded by many social institutions (i.e. insurance companies) as:

> [E]xtremely serious, disabling, or even lethal conditions . . . without regard to the fact that many individuals with "abnormal" genotypes will either be perfectly healthy, have medical conditions which can be controlled by treatment, or suffer only mild forms of a disease. . . . As a result of these misconceptions, decisions by such institutions are made solely on the basis of an associated diagnostic label rather than the actual health status of the individual or family.

Id. at 481. It appears that the evaluation of genetic conditions by such institutions reflects a lack of understanding of such basic concepts as incomplete genetic penetrance, variable expressivity, and genetic heterogeneity. *Id.* at 479. *See generally* Andrea DeGorgey, Note, *The Advent of DNA Databanks: Implications for Information Privacy*, 16 AM. J.L. & MED., 381 (1990).

11. L. Andrews, *The Future of Confidentiality of Genetic Information*, *in* MEDICAL GENETICS: A LEGAL FRONTIER 209 (1987); *see* George P. Smith, II, *Genetics, Eugenics and Public Policy*, 1985 S. ILL. U. L.J. 435 (1985).

12. Andrews, *supra* note 11, at 187-88, 209. "Unlike an infectious disease, a genetic disorder is generally immutable." *Id.* "Thus, an inappropriate disclosure may . . . cause serious financial, emotional, and perhaps even physical harm to the individual in question." *Id.*

13. *Id. See* Neil A. Holtzman, *Recombinant DNA Technology, Genetic Tests, and Public Policy*, 42 AM. J. HUM. GENETICS 624 (1988). *See generally* George P. Smith, II, *Biotechnology and the Law: Social Responsibility or Freedom of Scientific Inquiry?*, 36 MERCER L. REV. 437 (1988). One leading commentator has proposed four basic privacy rules for DNA databanks. *See* George J. Annas, *Privacy Rules for DNA Databanks: Protecting Coded "Future Diaries"*, 270 JAMA 2346, 2349 (1993). First, "[n]o such databanks

this context, genetic discrimination has been defined as "discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the 'normal' genome in the genetic constitution of that individual."[14] Individuals identified at risk are:

> (1) those . . . who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease, (2) individuals who are heterozygotes (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic, (3) individuals who have one or more genetic polymorphisms that are not known to cause any medical condition, and (4) immediate relatives of individuals with known or presumed genetic conditions.[15]

Forms of genetic discrimination will most likely appear in two contexts: employment and insurance. This is because individuals such as those mentioned above are asymptomatic or presymptomatic and therefore not readily identified.[16] Both employers and insurers may believe that such discrimination is warranted for the profitable conduct of business.[17] Furthermore, employers and insurers generally have access to detailed medi-

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should be created or commence storing DNA samples until" public notice and justification are given for establishing such a bank, "a privacy impact statement has been prepared and filed with a designated public agency" and a burden has been placed on the bank to prove that it advances a significant medical or societal goal. *Id.* Second, no collection or storage of DNA samples can be undertaken without prior written agreement setting forth the purposes and uses (including commercial) permitted of the samples and recognized guarantees of individual access to all samples and records thereof, given together with a right to not only correct inaccurate information but an additional right recognized to order the destruction of the sample should the databank change significantly its identity or, for that matter, cease operation altogether. *Id.* Third, strict security policies should be set which require the DNA samples to be used exclusively for the purposes for which they are collected—with access by third parties being controlled strictly. *Id.* Fourth, "[m]echanisms should be developed to notify and counsel those whose DNA samples are in storage when new information that can have a significant health impact on the individuals is obtainable, from their stored DNA sample." *Id.*

14. Marvin R. Natowicz et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS 465, 466 (1992). The authors "distinguish genetic discrimination from discrimination based on disability caused by altered genes" and thereby clarify the point that genetic discrimination is not based on any notion of the present function of the individual; rather the discriminating party relies on that individual's genotype to assess risk of future dysfunction. *Id.* As discussed later in this essay, current federal law does not address such discrimination.

15. Natowicz, *supra* note 14, at 466.

16. *Id.* *See* U.S. CONG., OFFICE OF TECHNOLOGY ASSESSMENT, GENETIC MONITORING AND SCREENING IN THE WORKPLACE (1990).

17. *See* Natowicz, *supra* note 14, at 467.

cal records of their employees or insureds.[18] For example, a job applicant may be subject to employment discrimination based on information obtained through genetic testing for several reasons: increased medical and insurance premiums, absenteeism, lowered productivity, enhanced risk in the line of duty, and concomitantly, greater worker's compensation liability.[19] In the area of insurance, genetic testing potentially undermines the principle that the insurer and the insured should be afforded identical information concerning the risk of an insured individual becoming ill.[20] The availability of the genotype of a particular individual either to the insurer or to the insured alone presents the possibility of adverse selection.[21] For example, an individual who knows he or she is at risk for developing Huntington's chorea will buy more "life or health insurance knowing that he or she is at increased risk of death" or serious illness.[22] Alternatively, an insurer with information suggesting that an applicant is in a high-risk category will likely severely limit or not offer coverage.[23]

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18. *Id.* at 466-67. *See* Mark A. Rothstein, *Genetic Screening in Employment: Some Legal, Ethical and Societal Issues*, 1 INT'L J. BIOETHICS 239 (1990); Rick Weiss, *Bio-Menace: Genetic Discrimination*, WASH. POST, Feb. 19, 1989, at D3. It is to be remembered that while not all employment discrimination is inefficient, this does not mean "that it is or should be lawful." RICHARD A. POSNER, ECONOMIC ANALYSIS OF LAW 337 (4th ed. 1992).

19. Nobles, *supra* note 2, at 2089. A more accurate measure of safety risk, instead of utilizing genetic testing, would be a test of an individual's actual capacity to function in a safety sensitive job. Council on Ethical and Judicial Affairs, *Use of Genetic Testing of Employees*, 226 JAMA 1827, 1828 (1991).

20. Nobles, *supra* note 2, at 2089. Over time, as the costs of genetic testing decrease and the degree of accuracy increases, insurers may find it not only cost effective to screen genetically prospective clients but indeed a competitive necessity. The central problem for insurers who either perform genetic testing themselves or obtain genetic information about such tests performed independently, is that this practice would lead in all likelihood to, discrimination (i.e. higher premiums or rejection altogether) against those who carry genes or genetic markers which dispose them to future illness. And interestingly, because each individual has potentially anywhere from four to eight genes which can cause disease, everyone seeking to enter the active work force is at risk for being genetically discriminated, against by aggressive high-tech insurance companies. Susan O'Hara, Note, *The Use of Genetic Testing in the Health Insurance Industry: The Creation of a "Biologic Underclass"*, 22 SW. U. L. REV. 1211, 1220-25 (1993); Shannon Brownless & Joanne Silberner, *The, Assurances of Genes*, U.S. NEWS & WORLD REPORT, July 23, 1990, at 57; Sandra Blakeslee, *Genetic Discoveries Raise Painful Questions*, N.Y. TIMES, Apr. 21, 1987, at C1 (quoting Dr. Aubrey Milunsky).

21. Nobles, *supra* note 2, at 2089.

22. *Id.*

23. *Id.* at 2090. Florida, Louisiana, New Jersey, and North Carolina have enacted legislation prohibiting discrimination in employment and insurance based on carrying the sickle-cell trait, hemoglobin C trait, Thalessemia, Tay-Sachs or cystic fibrosis. FLA. STAT., ch. 448.076 (1991); LA. REV. STAT. Ann. §§ 22:652.1, 23:1002A (West 1992); N.J. REV. STAT. § 10:5-12, 10:5-5 (1992); N.C. GEN. STAT. §§ 58-51-45, 58-58-25, 95-28-1 (1992).

The prospect of refusing to provide insurance to individuals because of a genetic trait is inequitable and contrary to public policy.[24] First, carriers of defective genes may never develop symptoms that affect their ability to function.[25] More important, however, such disparate treatment and resulting risk minimization vitiates the purpose of traditional private insurance as a risk-spreading mechanism.[26]

The first part of this essay evaluates the contemporary focus of the genetic revolution as seen through the Human Genome Initiative, a project that brings not only great hopes for new advancements in genetic knowledge designed to control disease and minimize human suffering, but raises real fears of unabated invasions of personal privacy that in turn would lead to discrimination for those individuals found to be genetically handicapped. The extent to which this central fear is justified is explored within the present context of the Genome Initiative, together with past genetic screening practices.

Next, the four basic types of genetic engineering currently available for use will be discussed as a background for analyzing the impact of these technologies on society's preoccupation with biological determinism. The ethical and philosophical conundrums created by the new genetics will in turn be considered with the realization that the theories for resolving these issues impact directly upon the formation of legal norms.

The essay then explores constitutional and legislative protections for individuals who, as a result of a particular genetic makeup, might be subject to discrimination. To this end, it first examines safeguards from discrimination based on genotype arguably afforded to individuals under the Equal Protection Clause of the Fourteenth Amendment to the Constitution. The essay then proceeds to examine the extent to which the confidentiality of genetic material is protected by the fundamental right to privacy derived from the Due Process Clause of the Fourteenth Amendment to the Constitution. Finally, the essay analyzes the Human Genome Privacy Act, one legislative attempt to provide individuals protection from discrimination based upon genotype.

The essay concludes that while there are risks associated with the pursuit and development of genetics, man's dehumanization and depersonalization need not be fostered as a consequence of the Human Genome Initiative. Rather, so long as science pursues its basic quest for knowl-

24. Nobles, *supra* note 2, at 2090.
25. *Id.*
26. *Id.*

edge with the purpose of establishing truth and integrity, and promotes the goal of minimizing human suffering and maximizing social good, the noble integrity of evolution and genetic progress will be preserved and irrational fears of eugenic supremacy being advanced by genetic screening programs will be dispelled. Restraining scientific inquiry and the application of its results should be limited only to actions considered unreasonable or contrary to public policy or in violation of constitutional norms.

I. THE HUMAN GENOME INITIATIVE

The human genome refers simply to the twenty-three pairs of chromosomes that all humans carry within which all human genes reside—and, more specifically, those genes that contribute directly to traits such as height, eye color, the shape of body parts, and human behavior.[27] Diseases develop when alterations, known as mutations of the genes, occur. In all, "more than two thousand disease conditions have their origins in single gene defects."[28]

The Human Genome Initiative is an undertaking funded by the U.S. Congress and coordinated by the United States Department of Energy and the National Institutes of Health (NIH). The initiative will complete "mapping" all 50,000 to 100,000 human genes within fifteen years.[29] Interestingly, there is no single human genome project in the United States. Rather, three major organizations—the NIH, the Department of Energy (DOE), and the Howard Hughes Medical Institute—finance specific aspects of an overall "initiative" on genome mapping. Simultaneous work efforts are also ongoing in other countries and by a private organization, the Human Genome Organization (HUGO).[30]

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27. Jon Beckwith, *Foreword: The Human Genome Initiative: Genetics' Lighting Rod*, 17 AM. J.L. & MED. 1, 2 (1991). *See* MAXINE SINGER & PAUL BERG, GENES & GENOME: A CHANGING PERSPECTIVE (1991).

28. Catherine M. Valerio Barrad, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1043 (1993).

29. Seth Lubove, *Genome Wildcatters*, FORBES, Feb. 3, 1992, at 97; James D. Watson, *The Human Genome Project: Past, Present and Future*, 248 SCIENCE 44 (1990). *See generally* J. BISHOP & M. WALDHOZ, GENOME: THE STORY OF THE MOST ASTONISHING SCIENTIFIC ADVENTURE OF OUR TIME—THE ATTEMPT TO MAP ALL THE GENES IN THE HUMAN BODY (1990).

30. *See* MEDICAL RESEARCH COUNCIL, HUMAN GENOME RESEARCH: A REVIEW OF EUROPEAN AND INTERNATIONAL CONTRIBUTIONS (Diane J. McLaren ed., 1991); OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, MAPPING OUR GENES: GENOME PROJECTS: HOW BIG, HOW FAST? (1988). *See also* George J. Annas, *Mapping the Human Genome and the Meaning of Monster Mythology*, 39 EMORY L.J. 629, 637 (1990); John C.

As of March, 1993, 2,736 of the targeted genes "had been 'mapped'—located precisely on one of the twenty-[three] human chromosomes [pairs]."[31] "Of those, 682 are known to be associated with human disease when they occur in mutant form."[32] "In 321, researchers have decoded at least part of the 'sequence', or precise chemical structure, which is the first step in determining precisely how a gene works."[33]

The driving motive behind the Human Genome Initiative is then quite simple and direct: the identification and eradication of all genetically based disease. With more than 2,000 conditions recognized as having their origins in single gene defects,[34] the ultimate success of the Initiative holds awesome opportunities for improving the health of all world citizens and minimizing human suffering from disease.[35] Yet, the secrets of the genome—when revealed—will generate a whole array of what-if fears: from the unbridled use of genetic information to advance a program of positive eugenics[36] to concerns that disclosure of an individual's genetic profile and his susceptibility to illness, will, in turn, form "the basis for discriminatory action or stigmatization."[37] The possible result is that an insurer will "refuse to pay medical costs if an individual elects not to undergo a recommended treatment, or if a child with a prenatally identified genetic defect is born."[38]

Equally worrisome is the fear that the "[w]idespread delineation of genetic profiles could result in centralization of the [genetic] information much as credit information is centralized today."[39] Because DNA sequence data bases are prone to error, there is also concern that even in the event gene mapping were to become routine, "comparison of an individual's genetic profile to an error-ridden prototype could have the same

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Fletcher, *Where in the World are We Going with the New Genetics?* 5 J. CONTEMP. HEALTH L. & POL'Y 33 (1989).

31. David Brown, *Filling in Gene Map, But Far From Home*, WASH. POST, Mar. 8, 1993, at A3; Daniel E. Koshland, *Sequences and Consequences of the Human Genome*, 246 SCIENCE 189 (1989).

32. *Id.*

33. *Id.*

34. Barrad, *supra* note 28, at 1043.

35. *See* Smith, *Manipulating the Genetic Code: Jurisprudential Conundrums*, *supra* note 2, at 733; *see also* Rick Weiss, *The Good, the Bad, & the Unknown*, WASH. POST, Oct. 11, 1994, (Health Magazine), at 7.

36. *See* GEORGE P. SMITH, II, GENETICS, ETHICS AND THE LAW, ch. 5 (1981). *See also* PHILIP REILLY, GENETICS, LAW AND SOCIAL POLICY 120 (1977).

37. *Id.*

38. Barrad, *supra* note 28, at 1046.

39. *Id.* at 1047.

stigmatizing effect as do false positives on drug tests and tests for the HIV antibody."[40]

Genetic Knowledge

Once a "disease gene" is discovered, the announcement of its discovery normally incorporates a suggestion that treatments are forthcoming. Yet discovering the mechanism of a disease is not the same as knowing how to alter that mechanism. With genetic information of this type, however, at least a chance is created for developing an effective therapy to combat the genetic disease.[41]

The "heuristics of fear" all too often blot out rational analysis of emerging genetic knowledge.[42] This adds little to the need to "promote medically and ethically informed public discussion."[43] This discussion should occur within "'communities of moral discourse' in which the scientific, medical, ethical and political issues are engaged by informed and intelligent persons who represent different interests and different perspectives on the nature of humanness and human well-being."[44] Caution should always be the watch-word, however, in examining genetic assumptions; and over-simplification of genetic findings should be avoided.[45]

As much as law should seek to avoid ambiguity, it should not rely on science for definitive answers; for science—within its own sphere—simply does not offer unambiguous answers.[46] Two forms of uncertainty are inherent in any scientific undertaking: one is "conceptual" and derives from fundamental changes in those concepts engendered by the new biotechnologies and the other is termed "occurrence" and applies to select issues that cannot be addressed readily.[47]

The "image of neutrality" that science has sought to cultivate or sell "is largely a myth originating in the efforts of scientists to maintain auton-

40. *Id.*

41. Brown, *supra* note 31, at A3.

42. *See* HANS JONAS, THE IMPERATIVE OF RESPONSIBILITY: IN SEARCH OF AN ETHIC FOR THE TECHNOLOGICAL AGE 26-27 (1984).

43. James M. Gustafson, *Genetic Therapy: Ethical and Religious Reflections*, 8 J. CONTEMP. HEALTH L. & POL'Y 183, 190 (1992).

44. *Id.* at 199, 200.

45. Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L. REV. 313, 348 (1993).

46. *Id.* at 343, 345.

47. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE, BIOMEDICAL & BEHAVIORAL RESEARCH, SPLICING LIFE: A REPORT ON THE SOCIAL & ETHICAL ISSUES OF GENETIC ENGINEERING WITH HUMAN BEINGS 22 (1982).

omy" and thus "blunt pressures from the church and from the state" for intervention and control.[48] Indeed, "the history of science is replete with cases where the choice of research topics, the nature of scientific theories, and the representation of research results are socially constructed, and shaped by cultural forces, to reflect . . . assumptions of particular societies at particular times."[49]

In 1990, the federal government's Center for Biologics, Evaluation and Research at the Food and Drug Administration (FDA) approved efforts to undertake human gene therapy.[50] Recognized as a "radical but unproven" method of fighting disease, the therapy involves the transfer of genetic information contained in DNA into specific cells to replace absent or deficiently functioning genes within those cells.[51] Initial experimentation trials will focus on the treatment of two different diseases: adenosine deaminase (ADA), a rare and congenital immune system defect, and metastatic melanoma, an advanced malignant cancer, virtually untreatable once it invades secondary organs.[52]

II. GENETIC ENGINEERING FORMS

According to Dr. W. French Anderson, there are four levels of the application of genetic engineering: somatic cell gene therapy (SCGT), germ line therapy (GLGT), enhancement genetic engineering (EGE), and eugenic engineering.[53] Each of these applications raises complex ethical

48. Dreyfuss & Nelkin, *supra* note 45, at 339-40. For example, the authors point to the evolution of Darwin's theory of Natural Selection into a theory of Social Darwinism as a biological defense of the changing forces of industrialization. *Id.* They also point out that Gregor Mendel's theories of genetics and Francis Galton's eugenic principles "were being used to prove that deviant behavior and low IQ were hereditary." *Id.*

49. *Id.* at 339. William Booth, *FDA Approves Cancer Therapy for Use in Cancer Treatment*, WASH. POST, Nov. 14, 1990, at A1, A12. *See generally* W. French Anderson, *Human Gene Therapy: Scientific and Ethical Considerations*, 10 J. MED. & PHILOSOPHY, 275 (1985).

50. Booth, *supra* note 49, at A12. *See* Francois Gros, *Gene Therapy: Present Situation, and Future Prospects*, 2 NEUROMUSCULAR DISORDERS 75 (1992); Cournoyer et al., *Gene, Therapy: A New Approach for the Treatment of Genetic Disorders*, 47 CLINICAL PHARMACOLOGY & THERAPEUTICS 1 (1990).

51. Booth, *supra* note 49, at A1. *See also* Larry Thompson, *Gene Therapy in Humans Approved*, WASH. POST, July 31, 1990, at A3; Larry Thompson, *Medicine's Four-Year-Old Pioneer: First Gene-Therapy Patient Opens Door to Treating 4,000 Inherited Diseases*, WASH. POST, Sept. 25, 1990, (Health Magazine), at 8-9.

52. Booth, *supra* note 49, at A1, A12. *See also* Larry Thompson, *Scientists Turn Off Growth of Cancer Cells: Experiments in Gene Therapy Show Promise in Laboratory*, WASH. POST, Sept. 11, 1990, (Health Magazine), at 6. *See generally* Milo Gibaldi, *Human Gene Therapy*, 13 PHARMACOTHERAPY 79 (1993).

53. In early September, 1994, a federal advisory board voted to allow some fast-track

and scientific issues.[54] The most amenable approach to solving the effects of a broad spectrum of inherited diseases is to be found with somatic cell gene therapy—yet, it is the only one of four that is yet to be justified through scientific verification and ethical acceptance.[55]

Somatic cell gene therapy, the first level, involves a gene transfer into the somatic (body) cells of a human in order to correct a genetic defect.[56] If the therapy is developed fully, it would result—when used—in replacing defective or absent enzymes or proteins (the product of genes) that are necessary for a cell to function properly. Already by 1992, within the National Institutes of Health and its Recombinant DNA Advisory Committee, eleven gene therapy trials had been approved and seven more were under consideration. It is expected that within the next two years, applications will quadruple.[57]

Still in its infancy, the second level, germ line therapy, seeks to insert a gene into the reproductive cells of the germ cells of an afflicted patient.[58] In addition to combatting genetic disease, other ailments, such as cancer,

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proposals to be submitted directly to the Food and Drug Administration by scientists wishing to perform certain genetic experiments on people with the purpose of providing treatment for genetic diseases. Rick Weiss, *Regulations are Eased on Genetic Experiments*, WASH. POST, Sept. 20, 1994, (Health Magazine), at 5. Previously, scientific proposals of this nature had to be submitted to a committee within the National Institutes of Health Committee composed of scientists, ethicists and community members, where the request was evaluated in a public forum and testimony taken from patient advocates and concerned citizens alike. *Id.* The new FDA procedure bars public participation. *Id.* The "fast track" procedure was promoted by AIDS activists because of their concerns that new genetic therapies for the treatment of AIDS had become mired in the federal bureaucracy. *Id.*

Some members of the DNA Advisory Committee of NIH, a committee that would be bypassed in some cases by the new FDA rules, have expressed concern that many gene therapy protocols reviewed by them are not only poorly designed but have not been tested adequately on animals and commonly understate the risks or overstate the potential benefits. *Id.* The members argue that problems of this nature have a greater chance of being resolved if considered in open meetings rather than under the fast track FDA procedure. *Id.*

54. Anderson, *supra* note 49, at 285-87. *See generally Hearings on Human Genetic Engineering Before Subcomm. on Investigation and Oversight of the Committee on Science and Technology*, 97th Cong., 2d Sess. (1982); Rick Weiss, *Scientists Making Gains Against Inherited Diseases Find Their Task Harder Than Expected: Gene Therapy at the Crossroads*, WASH. POST, Oct. 18, 1994, (Health Magazine), at 12.

55. Anderson, *supra* note 49, at 284-86.

56. Robin Herman, *Tinkering With the Essence of Humanity: Scientists and Theologians Debate the Morality of Genetic Engineering*, WASH. POST, Oct. 8, 1991, (Health Magazine), at 6; Anderson, *supra* note 49, at 275.

57. Robin Herman, *Gene Therapy is No Longer a Rarity*, WASH. POST, Jan. 21, 1992, (Health Magazine), at 7.

58. Herman, *supra* note 56, at 6.

heart and vascular disease, could be treated by this type of gene therapy. While germ line changes have been accomplished successfully in mice, germ line therapy has yet to be performed in humans.[59]

History was made in September, 1990, when a four-year-old girl received the world's first gene therapy in the treatment of an immunological disorder.[60] Another milestone was achieved when in January, 1992, a two-year-old child who was suffering from a neuroblastoma tumor was treated with genetically altered bone marrow cells.[61] Termed gene therapy, this medical procedure altered the genetic material of a patient in order to combat disease at its cellular source. It subsequently was performed on twenty-two patients and became a viable strategy for uncovering new approaches to fighting incurable diseases. This therapy has not only been tested, developed, and applied in the United States, but has been proposed and/or initiated in Canada, China, Italy, France, and Japan.[62]

The third level, enhancement engineering, is effected by inserting a gene into a patient's reproductive tissues, thus correcting the disorder in his or her potential offspring.[63] For example, in order to "'enhance' a known characteristic . . . an additional growth hormone gene" could be inserted into a normal child.[64] While the enhancement of somatic cells is now feasible and has been performed in animal experiments, the enhancement of germ-line cells is not yet technically feasible.

The fourth level of engineering—recognized as eugenic in focus—seeks, by definition, to "alter or 'improve' complex human traits, each of which is coded by a large number of genes: for example, personality, [and] intelligence."[65] This level is not thought to be feasible in the foreseeable future. Indeed, the processes associated with it may be "so complex that it may never be feasible."[66]

A. Toward a Principle of Biological Determination

Today's society exhibits a new and discernible preoccupation with biological determinism. Successes in developing genetic tests that have lo-

59. *Id.*
60. Herman, *supra* note 57, at 7.
61. *Id.*
62. *Id.*
63. *Id.*
64. *Id.*
65. *Id.*
66. Herman, *supra* note 56, at 6.

cated markers reflecting predisposition to single gene disorders have engendered "hope that more complex conditions such as cancer, drug dependency and mental illness, will ultimately be predictable."[67] Building upon the limited successes with Huntington's chorea, many "states now mandate the use of genetic testing for conditions such as phenylketonuria (PKU) in newborn infants."[68]

Biological determinism evolves from the principle of genetic essentialism that posits personal traits—such as mental illness, homosexuality, aggressive personality, dangerousness, exhibitionism, stress, and shyness—have a genetic or biological disposition and, indeed, are predictable and determinable at conception.[69] Thus, the social context in which the traits are manifested is minimized under this principle.[70] In a word, biological determinism recognizes essentially that one's fate is determined by genetic inheritance.[71]

B. Contemporary Perspectives

A recent survey conducted by Louis Harris and Associates for The March of Dimes polled 1,000 people in the United States regarding their views of genetic testing and gene therapy. Although those surveyed did not completely understand all the issues, 79% expressed their willingness to undergo gene therapy if necessary, and 88% said they would have their children undergo such therapy in order to prevent or cure a genetic dis-

67. Dreyfuss & Nelkin, *supra* note 45, at 314.

68. *Id.* For an historical overview of early state mandated PKU testing between 1963 and 1968 and the state legislative citations to the 43 states where such genetic testing is required, see Reilly, *supra* note 36, at 37, 49-52, ch. 4.

69. Dreyfus & Nelkin, *supra* note 45, at 320.

70. *Id.* at 320-32. See Owen D. Jones, *Sex Selection: Regulating Technology Enabling the Predetermination of a Child's Gender*, 6 HARV. J.L. & TECH. 1 (1992), where a justification of sex selection is that its use serves to reduce or eliminate "certain sex-linked diseases such as hemophilia, Cooley's Anemia, Down's syndrome and more than 400 others, that increase aggregate social anxiety and tax society's medical and financial resources." *Id.* at 21.

71. Dr. James Watson, Director of the Human Genome Initiative, said, "our fate is in, our genes." Leon Jaroff, *The Gene Hunt*, TIME, Mar. 20, 1989, at 62, 67. Social analysts differ in their views on the extent to which the pervasiveness of genetic determinism will be felt. For, while the history of eugenics and racial hygiene was uneven and disturbing, it occurred in an historical atmosphere where no countervailing forces of critical scrutiny existed both from inside or outside the scientific and medical communities. The present genome project, to the contrary, not only invokes scrutiny but has built standards for review into its operative procedures. ROBERT COOK-DEEGAN, THE GENE WARS: SCIENCE, POLITICS, AND THE HUMAN GENOME 254 (1994).

ease that would usually be fatal if undetected.[72] Approximately three-quarters of those polled expressed concerns that gene therapy be undertaken only according to "strict regulations."[73] More than half of those surveyed stated their belief that when a genetic disease is discovered, someone needs to be apprised of this fact. Of those, approximately one-third believed an employer should be advised of the genetic disease, 58% concluded insurers should be informed, and 98% concluded one's spouse or fiancé should be told. In addition, 47% of those surveyed favored experimental gene therapy if its goal was to improve physical characteristics, while 42% would allow gene therapy when its goal was to improve a child's intelligence.[74]

III. Ethical and Philosophical Conundrums

The new genetics raises no new ethical problems in the sense of unique dilemmas not heretofore seen. The core issues of present ethical problems in this field were indeed recognized in the late 1960s with the introduction and widespread use of amniocentesis and carrier screening.[75] The new genetics, however, will "magnify both the complexity and frequency of these problems."[76] Behind the current problems facing society is a national and international failure by medical geneticists to form, and thereby validate in writing, agreements, protocols, or compacts that address these ethical problems.[77] Instead, a blind adherence to oral traditions is pursued. Clearly, without uniform ethical standards within the scientific community, the power-brokers in human genetics are less ac-

72. Sandy Rovner, *Many Americans Say Gene Therapy Okay*, Wash. Post, Sept. 29, 1992, (Health Magazine), at 5. *See* Howard Markel, *The Stigma of Disease: Implications of Genetic Screening*, 93 Am. J. Med. 209 (1992).

73. Rovner, *supra* note 72, at 5.

74. *Id.* A December, 1993, poll of 500 adult Americans taken by Yankelovich Partners, for TIME/CNN found a marked ambivalence among the respondents regarding genetic research and its applications. Philip Elmer-Dewitt, *The Genetic Revolution*, Time, Jan. 17, 1994, at 48. For example, 49% said they would not take a genetic test that could tell them what diseases they were likely to suffer later in life, while 50% said they would like to know. *Id.* Most respondents strongly opposed the uses of human genetic engineering except for the purpose of curing disease or enhancing agricultural production. *Id.* Fifty-eight percent, thought altering human genes was against the will of God. *Id.* Ninety percent said it should be illegal to allow insurance companies to use genetic tests in order to decide whom to insure. *Id.*

75. John C. Fletcher & Dorothy C. Wertz, *Ethics, Law & Medical Genetics: After the Human Genome is Mapped*, 39 Emory L.J. 747, 759 (1990).

76. *Id.*

77. *Id.*

countable to the public for their actions.[78]

According to John C. Fletcher and Dorothy C. Wertz, the eight problems confronting geneticists and their patients, for which no standard ethical structure exists for approaching resolutions, are:

1. Unequal access or non-access to services;
2. Moral conflict and concern over abortion choices for genetic reasons in pregnancies;
3. Maintaining confidentiality in patient-geneticist relationships and preventing non-consenting disclosures;
4. Protecting persons at higher genetic risks from invasions of privacy by institutional third parties such as government agencies, health insurers and employers;
5. A variety of disclosure dilemmas focusing on medical genetics' potential to reveal without permission psychologically sensitive information that can easily disrupt family and marital relations;
6. Non-medical and non-genetic indications for pre-natal diagnosis;
7. Whether genetic services should be voluntary or mandatory;
8. The nature and extent of nondirective genetic counseling for mentally or physically incapacitated patients.[79]

Professor John C. Fletcher, Professor of Biomedical Ethics and Religious Studies, and Director of the Center for Biomedical Ethics at the University of Virginia Medical School, conducted a study in 1984 of 1,053 geneticists at twenty-four genetics centers in twelve nations.[80] In this study, respondents ranked ten major ethical issues confronting the international community of geneticists:

1. Increased demand for genetic services;
2. Carrier screening;
3. Allocation of limited resources;
4. New treatments for genetic diseases;
5. Environmental damage to the unborn;
6. Screening for cancer and heart disease with genetic tests;
7. Research involving the human embryo;
8. Genetic screening in the workplace;
9. Long-range eugenic concerns;
10. Sex pre-selection.[81]

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78. *Id.* *See* SMITH, *supra* note 36, ch. 1.

79. Fletcher & Wertz, *supra* note 75, at 761-65. *See generally*, George P. Smith, II, *Toward an International Standard of Scientific Injury*, 2 HEALTH MATRIX 167 (1992).

80. Fletcher & Wertz, *supra* note 75, at 774.

81. *Id.* at 774. "As the Human Genome Project quickens, tens, if not hundreds, of new

A. Conflicts and Compatibilities

These two sets of ethical-philosophical problems share a primary concern regarding the wide-reaching effects of genetic screening. Even within this isolated issue, there is considerable debate among scholars yielding antipodal viewpoints. Some scholars prefer to examine the ethical positions with the goal of grouping them into more manageable categories or schools of thought.[82] Yet, even as these syntheses highlight the vast range of conflicting ethical opinion, one central conflict recurs time and time again: which is the more significant analytical value—quality of life or sanctity of life?[83]

Theologian Bernard Ramm agrees: "I think both Christian and non-Christian are slowly coming to the conviction that the supreme norm in ethics is the quality of life and not the sheer fact of life."[84] To be sure, this issue is not confined solely to ethical and theological theories. Living wills and legislation that ensures death with dignity have captured public attention and sensitized many to ultimate quality of life considerations.[85]

The most likely objective of selective genetic screening is improvement in the quality of life by identifying carriers and victims of genetic disease. Reduction of the incidence of these illnesses and the suffering they cause could be achieved through counseling, abortion, and genetic engineering techniques.[86] Although admittedly the ethical issues are complex, they

genetic screening tests will compete for introduction into routine clinical practice." Sherman Elias & George J. Annas, *Generic Consent for Genetic Screening*, 330 NEW ENG. J. MED. 1611, 1611 (1994). Consequently, it is urged that new strategies based on general or, "generic" consent should be developed for genetic screening. The aim of which would be to provide sufficient information to permit patients to make informed decisions about carrier screening, yet avoid the information overload that could lead to 'misinformed' consent *Id.* The stakes in reproductive genetics are inevitably high because they involve exercise of a right to decide whether or not to engage in genetic testing—balanced by a coextensive right, to *refuse* if a potential harm—in terms of stigma, for example—outweighs the benefits derived from it for the at-risk individual or his family. *Id.*

82. Bernard Ramm, *An Ethical Evaluation of Biogenetic Engineering*, 26 J. AM. SCI. AFFILIATION 137 (1974); Richard McCormick, *Genetic Medicine: Notes on the Moral Literature*, 33 THEO. STUD. 531 (1972).

83. *See generally* George P. Smith, II, *Quality of Life, Sanctity of Creation: Palliative, or Apotheosis?* 63 NEB. L. REV. 709 (1984).

84. Ramm, *supra* note 82, at 142.

85. GEORGE P. SMITH, II, AUTONOMY IN HEALTH CARE DECISIONS (1989). *See also* George P. Smith, II, *Reviving the Swan, Extending the Curse of Methuselah or Adhering to the Kevorkian Ethic?*, 2 CAMB. Q. HEALTHCARE ETHICS 49 (1993); George P. Smith, II, *All's Well That Ends Well: Toward a Policy of Assisted Rational Suicide or Merely Enlightened Self-Determination?*, 22 U.C. DAVIS L. REV. 275 (1989).

86. SMITH, *supra* note 36. *See* George P. Smith, II, *Genetics, Eugenics, and the Family: Exploring the Yin and the Yang*, 8 UNIV. TASMANIA L. REV. 4 (1984).

ultimately are reducible to the most elemental questions of who is to live and who is to die. Moreover, the question still remains as to who will justify these decisions? Thus, even though the central dilemma is fairly well structured, the solution is far from settled.

For the late Professor Joseph Fletcher, the evolution from the "old vitalistic undiscriminating sanctity-or-quality-of-life ethics . . . to a responsible, decisional quality-of-life ethics"[87] injects desirable elements of control and choice. It thus becomes a moral responsibility to control "reproduction through sex selection or preemptive abortion in response to a genetic defect."[88] Fletcher underscores his argument for the necessity of genetic screening with a graphic example:

> To go right ahead with coital reproduction in many couples' cases, is like walking down a line of children blindfolded and deliberately maiming every fourth child. It is cruel and insane to deprive normal but disadvantaged children of the care we could give them with the $1,500,000 we spend in public costs for preventable retardates.[89]

Fletcher adds what may be the credo of situation ethicists: "Ethics is not loftily independent of economics and utilitarian or distributive justice."[90] And, what if the populace fails to make responsible reproductive choices voluntarily? "[S]ometimes it is more compassionate to force [the moral thing] to be done than to sacrifice the well-being of the many to the egocentric 'rights' of the few. This obviously is the ethics of a sane society."[91]

Others suggest that the fundamental question to be addressed is: Simply because some things can be done, should they be undertaken?[92] For the late Paul Ramsey, there was a definite answer.

> The sine qua non of any morality at all, of any future for humanism, must be the premise that there may be a number of things that we *can* do that *ought* not to be done. Our common inquiry must be to fix upon those things that are worthy of man . . . . Any other premise amounts to a total abdication of human

87. JOSEPH FLETCHER, THE ETHICS OF GENETIC CONTROL 156-57 (1974).

88. *Id.* at 157.

89. *Id.* at 160.

90. *Id.*

91. *Id.* at 180. Other ethicists, geneticists and philosophers have asked, for example, whether or not a basic right exists for every person to be born mentally and physically sound and whether society has a responsibility to support "the burden of genetic misfortune" among its citizens. Bentley Glass, *Heredity and Ethical Problems*, 15 PERSPECTIVES IN BIOLOGY & MED. 237, 252 (1972). *See also* Smith, *supra* note 4, at 10. *But see* LAURENCE KARP, GENETIC ENGINEERING, THREAT OR PROMISE 123 (1976).

92. Ron Docksai, *The Limits of Genetic Control*, 15 NEW GUARD 21 (1975).

> moral reasoning and judgment and the total abasement of man before the relentless advancement of biological and medical technology.[93]

While some moral philosophers remain forever optimistic that there is no real threat to either the concept of sanctity of life or the individual from genetic knowledge and its application,[94] others have continued to express a real fear that, with the new advances in technology, procreative decisions will become increasingly dehumanized. Professor Leon Kass frames his concern as follows: "At what price—in greater complexity of society or in our beliefs about what it means to be human—do we seek a technological fix for the human condition?"[95] The Roman Catholic Church, historically, the staunch defender of the principles of the sanctity of life, has cautioned that society must seek to secure justice through recognition of the inviolability of every person's life.[96]

A major counter-argument to that of the sanctity of human life recognizes that, in the abstract, this principle has never been truly implemented. Rather, it has been violated "innumerable times for the base purposes of war by the hangman's rope, by local abundance in a world always pocked by famine."[97] Thus, presumably, if man became the true master of his genetic fate, he would then rise to the challenge of expanding the meaning of life itself by devising a stronger species that does not succumb as easily to the ravages of the race.[98]

For some, visions of a new, eugenically sound species resurrect the specter of the Nazi atrocities, and it is within this context that Professor Paul Ramsey delivers his fillip to the quality of life argument:

> Still, no one should forget the judgment of the leading scholar of

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93. P. RAMSEY, FABRICATED MAN 150-51 (1970). *See generally* Robert Elliott, *Identity and the Ethics of Gene Therapy*, 7 BIOETHICS 27 (1993).

94. JOSEPH FLETCHER, THE ETHICS OF GENETIC CONTROL (1988); JOHN FLETCHER, *Applied Genetics: No Ultimate Threat*, 1 ENGAGE/SOCIAL ACTION 17, 27 (1973). *See* Fletcher, *supra* note 30, at 33.

95. Leon Kass, *The Future of Man, The Organism: The New Biology*, *in* AMERICA AND THE FUTURE OF MAN 55 (1974).

96. 16 NEW CATHOLIC ENCYCLOPEDIA 2 (1974). New genetic knowledge, which in turn allows for and in some cases promotes, the use of genetic testing, focuses—of necessity—upon prenatal testing that presents an option (for some) of abortion. COOK-DEGAN, *supra*, note 71, at 251. And, of course, the choice of abortion on the basis of expected disability forces the issue of whether predetermined quality in children is a desired social good. *Id.*

97. Robert L. Sinsheimer, *Prospects for Future Scientific Developments*, *in* ETHICAL, ISSUES IN HUMAN GENETICS 341, 345 (Hilton & Callahan eds., 1973). *See* James M. Gustafson, *supra* note 43, at 190.

98. Sinsheimer, *supra* note 97, at 348-50. *See generally* Smith, *supra* note 11.

> the Nazi medical cases: "Whatever proportion these crimes finally assumed, it became evident to all who investigated them that they had started from small beginnings .... It started with the acceptance of the attitude ... that there is such a thing as life not worthy to be lived."[99]

Quality of life arguments most assuredly do not lead all to the same conclusions. Accordingly,

> [q]uality of life should be sought by the cautious improvement of our cultural and environmental resource pools, and not by an impulsive over-emphasis upon manipulations of a gene pool whose dynamics and long-term mechanisms still elude us. We should improve the environment of our handicapped brethren, we should research means to elevate the intellectual capability of our Down's infants, we should seek means to cure phenotypic anomalies instead of alleviating their owners.[100]

The existence of so many diverse viewpoints that are so strongly held suggests a basic question: How does a society arrive at ethical norms? In a pluralistic society this is difficult, perhaps impossible, to answer. For some, religion dictates the construction of the ethical fabric. For others, a higher moral law directs ethical choices. But society is reactionary.[101] Being amoeba-like, it shapes itself around controversial issues, changing and adapting to their impact according to an elusive norm. "The touchstone of man's ... ethical choices, is simply his judgment of whether it is right and good for man. Man is the measure of all things."[102] This emphatically humanistic approach is echoed by Professor Joseph Fletcher who maintains that needs are, in actuality, moral stabilizers. "If human rights conflict with human needs, let needs prevail."[103] Even Father Richard McCormick, who argues it is necessary to "blow the whistle"[104] on Fletcher's type of reasoning, worries that Christian arguments "are not likely going to be very persuasive to a culture which, it can be argued, is comfort-bent, goal-oriented, technologically sophisticated, sexually trivi-

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99. PAUL RAMSEY, THE PATIENT AS PERSON 164 (1970).

100. Gastonquay, 4 ETHICS IN SCI. & MED. 129, 132 (1977).

101. *See* George P. Smith, II, *Procreational Autonomy v. State Intervention: Opportunity or Crisis for a Brave New World?* 2 NOTRE DAME J.L., ETHICS & PUB. POL'Y 635, 635-36 (1986).

102. Tracey Sonneborn, *Ethical Issues Arising from the Possible Uses of Genetic Knowledge*, *in* ETHICAL ISSUES IN HUMAN GENETICS 1, 5 (1973).

103. Joseph Fletcher, *Ethical Aspects of Genetic Controls: Designed Genetic Changes in Man*, 285 NEW ENG. J. MED. 782 (1971).

104. McCormick, *supra* note 82, at 533.

alized and deeply secularized."[105]

Yet, despite these concerns expressed by Father McCormick, and the slippery nature of the ethical decision-making process, the debate continues to rage. One philosopher has attempted to define the quality of life by a mathematical formula, the unspoken assumption being that quality of life is a proper consideration.[106] Another authority questions whether it is moral even to "speculate on social policy based on presumptive genetic differences between groups of individuals" when measures for genetic inheritance are still flawed.[107] The notion of calculating cost-benefit analysis when the stakes are human lives is as shocking to some as it is logical to others. Daniel Callahan sees such analyses as one-directional. He charges that they ignore the intangible benefits to a society that is willing to bear the costs of humane care.[108]

More than one ethicist is concerned that genetic screening will lead to a national intolerance of anyone "abnormal." Paul Ramsey sees this consequence of screening as "upgrading the concept of acceptable normality."[109] Undoubtedly, screening will not detect all defects. Leon Kass wonders if those who manage to "escape the net of detection and abortion" will be regarded as unfit to be alive.[110] Both Ramsey and Kass fear that the inevitable corollary is that aversion to abnormalities will lead to mandatory elimination of abnormalities,[111] and ultimately the same justifications for aborting "defective" fetuses may "simultaneously justify the killing of defective infants, children and adults."[112]

The lines have been drawn, but they delineate a spectrum of spectacular diversity. The philosophical rationale for genetic screening may well

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105. *Id.* at 552.

106. Anthony Shaw, *Defining the Quality of Life*, HASTINGS CTR. REP., Oct. 1977, at 11.

107. Marc Lappe, *What's in the Genes, Anyway*, 1 J. VAL. & ETHICS 272 (Summer 1976).

108. Daniel Callahan, *The Meaning and Significance of Genetic Disease: Philosophical Perspectives*, *in* ETHICAL ISSUES IN HUMAN GENETICS 83, 84-89 (1973).

109. Paul Ramsey, *Screening, An Ethicists' View*, *in* ETHICAL ISSUES IN HUMAN GENETICS 147, 160 (1993).

110. Leon Kass, *Implications of Prenatal Diagnosis for the Human Right to Life*, *in* ETHICAL ISSUES IN HUMAN GENETICS 185, 189 (1973).

111. Ramsey, *supra* note 109, at 159; *see generally*, Kass, *supra* note 110. It has been suggested that for genetic disorders, such as Tay-Sachs and anencephaly, abortion would be proper if these traits were discovered *in utero*. Yet, for Huntington's disease—where large variations exist in the severity and age of onset—there is greater latitude and perhaps a real choice between the finality of genetic determinism and the hope of environmental manipulation and scientific advancement. COOK-DEEGAN, *supra* note 71, at 252-53.

112. Kass, *supra* note 110, at 188.

rest on quality of life considerations. The rejoinder may remain an insistent concern for the sanctity of life and a warning against dehumanization in the face of inexorable technology. Between these two positions, the search continues for areas of compromise and accommodation.

IV. EQUAL PROTECTION

A. *Immutability As a Basis For Active Judicial Review*

In contrast to the lively ethical debate, little has been written about the extent to which an individual with an abnormal genetic trait as described above might be included in a suspect class and therefore benefit from the safeguards of equal protection.[113] The United States Supreme Court, however, has identified one criterion by which such an individual might be deemed a member of a suspect class.[114] This analytical framework applies strict scrutiny to a statute which focuses on an immutable charac-

113. At least one article examines the constitutional issues raised by the regulation of, genetic engineering. John B. Attanasio, *The Constitutionality of Regulating Human Genetic Engineering: Where Procreative Liberty and Equal Opportunity Collide*, 53 U. CHI. L. REV. 1274 (1986). Professor Attanasio explores the tension between the liberty and equality principles of American constitutionalism as applied to government regulation of positive genetic engineering, analyzing in particular whether equal protection jurisprudence guarantees the rights of a genetically engineered superior minority or of a genetically inferior majority. *Id.* at 1284. Our essay, however, limits itself to an examination of the extent to which discrimination against an individual by a state entity, based upon genetic material rather than a recognized suspect classification, is arguably proscribed by traditional equal protection, analysis. *See also* Janet A. Kobrin, *Medical Privacy Issue: Confidentiality of Genetic Information*, 30 UCLA L. REV. 1283, 1293 (1983) (genetic screening may involve a Fourteenth Amendment issue to the extent a genetic disease is confined to a specific race).

114. *See generally* Plyler v. Doe, 457 U.S. 202 (1982). This does not suggest that the Supreme Court has limited its reasoning in identifying a suspect class to one analytical framework. Rather the Court has adopted several formulations which illuminate the Court's treatment of certain classifications as suspect:

> Some classifications are more likely than others to reflect deep-seated prejudice rather than legislative rationality in pursuit of some legitimate objective. Legislation predicated on such prejudice is easily recognized as incompatible with the constitutional understanding that each person is to be judged individually and is entitled to equal justice under the law. Classifications treated as suspect tend to be irrelevant to any proper legislative goal. Finally certain groups, indeed largely the same groups, have historically been "relegated to such a position of political powerlessness as to command extraordinary protection from the majoritarian political process." The experience of our Nation has shown that prejudice may manifest itself in the treatment of some groups. Legislation imposing special disabilities upon groups disfavored by virtue of circumstances beyond their control suggests the kind of "class or caste" treatment that the Fourteenth Amendment was designed to abolish.

Id. at 216-17 n.14 (citations omitted); *see also* San Antonio Indep. Sch. Dist. v. Rodriguez, 411 U.S. 1, 28 (1973); Graham v. Richardson, 403 U.S. 365, 372 (1971); McLaughlin v.

teristic over which individuals identified by such characteristic have no control.[115] Although only one analytical tool in the panoply included under equal protection analysis, this "immutable characteristic" mode of inquiry reveals more clearly than others the theoretical underpinnings of equal protection jurisprudence that might be applied to discrimination based on a genetic trait.[116] Granted, this constitutional rule extends protection only to those individuals adversely affected by state action.[117]

Florida, 379 U.S. 184, 192 (1964); Hirabayashi v. United States, 320 U.S. 81, 100 (1943); United States v. Carolene Products Co., 304 U.S. 144, 152-53 n.4 (1938).

115. Bowen v. Gilliard, 483 U.S. 587, 603 (1986); Wygant v. Jackson Bd. of Educ., 476 U.S. 267, 301 (1985) (Marshall, J., dissenting); Cleburne v. Cleburne Living Ctr. Inc., 473 U.S. 433, 437-38, 442-45 (1985); Plyler v. Doe, 457 U.S. 202, 220 (1982); Schweiker v. Wilson, 450 U.S. 221, 229 (1981); Fullilove v. Klutznick, 448 U.S. 448, 496, 516, 519, 525 (1979) (Powell, J., concurring; Marshall, J., concurring; Stewart, J., dissenting); Caban v. Mohammed, 441 U.S. 380, 398 (1979) (Stewart, J., dissenting); University of Cal. Regents v. Bakke, 438 U.S. 265, 360-61 (1977) (Brennan, White, Marshall & Blackmun, JJ., concurring in part and dissenting in part); Craig v. Boren, 429 U.S. 190, 212 (1976) (Stevens, J., concurring); Johnson v. Robison, 415 U.S. 361, 375 (1974); Frontiero v. Richardson, 411 U.S. 677, 686-88 (1973); Weber v. Aetna Cas. & Sur. Co., 406 U.S. 164, 175-76 (1972).

116. These theoretical underpinnings have been most fully analyzed in the context of gay rights. In arguing that homosexuality should be treated as a suspect classification, commentators have relied upon, among others, the immutable characteristic basis for identifying a suspect class. Nan D. Hunter, *Symposium: the State of Civil Liberties: Where, do we go from here? Life After Hardwick*, 27 HARV. C.R.-C.L. L. REV. 531, 549-50, (1993); Note, *The Constitutional Status of Sexual Orientation: Homosexuality As a Suspect Classification*, 98 HARV. L. REV. 1285, 1299-1305 (1985). Indeed, a recent DNA study has provided yet more evidence of the immutable character of sexual preference. Dean H., Hamer et al., *A Linkage Between DNA Markers on the X Chromosome and Male Sexual Orientation*, 261 SCIENCE 321 (1993). *See also* Chandler Burr, *Homosexuality and Biology*, ATLANTIC MONTHLY, Mar. 1993, at 47; Christopher B. Daly, *Study of Twins Suggests Lesbianism Has a Genetic Component*, WASH. POST, Mar. 15, 1993, at A3.

In determining whether a particular classification is suspect, the majority of courts and, writers focus on the "stigma" and "opprobrium" attached to membership in that group and, that group's resulting unequal treatment. Note, *supra* at 1299 (citing Note, *Developments in the Law—Equal Protection*, 82 HARV. L. REV. 1065, 1127 (1969)). There are two other generally accepted criteria for suspectness, the "immutability" of the group's, defining qualities, *id.* (citing Frontiero v. Richardson, 411 U.S. 677, 686 (1973)), and the, status of the group as a "discrete and insular minority," *id.* (citing United States v. Carolene Products Co., 304 U.S. 144, 152 n.4 (1938)), have been the subject of bitter disagreements among theorists as to their relative significance. *Id.*; *see also* JOHN H. ELY, DEMOCRACY AND DISTRUST 163-64 (1980); Lawrence H. Tribe, *The Puzzling Persistence of Process-Based Constitutional Theories*, 89 YALE L.J. 1063, 1072-77 (1980).

117. The constitutional mandate of equal protection is directed to the states: "No States shall . . . deny to any person within its jurisdiction the equal protection of the laws." Note, *supra* note 116, at 1069-71 (1969) (quoting U.S. CONST. amend. XIV, § I). However, the Supreme Court has construed the amendment to apply to a broad area of "state responsibility." *Id.* (citing Burton v. Wilmington Parking Authority, 365 U.S. 715, 722 (1961)). Furthermore, the courts have recognized state action in a variety of forms and degrees of state involvement. *Id.* (citing United States v. Guest, 383 U.S. 745, 755-56 (1966)).

Nonetheless, the recognition of such rights has in the past served as a starting point for legislation applicable to private entities.

In *Frontiero v. Richardson*,[118] the United States Supreme Court introduced the concept that the possession of an immutable characteristic should be a basis for identifying a suspect status.[119] The immutable characteristic in *Frontiero* was sex, which the Court found, like race and national origin, to be determined solely by accident of birth.[120] The Court reasoned that the imposition of a particular disability on the members of a particular sex because of their sex would seem to violate the principle that legal burdens should be related to individual responsibility.[121] Justice Brennan, writing for the Court, however, carefully distinguished sex from such non-suspect statuses as intelligence or physical disability. Unlike intelligence or physical disability, the Court noted that sex frequently bears no relation to the ability to perform or contribute to society.[122] Finally, the Court characterized the impermissible result of distinctions based on sex as "invidiously" relegating the entire class of females to inferior legal status without regard to the actual capabilities of individual women.[123]

Similarly, to the extent such genetic information is publicly available, statutory distinctions based upon such markers have the identical invidious effect of relegating a class of individuals to inferior legal status. Such markers thus become a genetic scarlet letter, a badge or incident of genetic dissimilarity or variation which although always present in the genetic material of a class of individuals, bears no relationship to their functionality as members of society.[124] The application of this analytical framework to the genetic abnormalities described above leads to a con-

118. 411 U.S. 677 (1973).

119. *Id.* at 686-87.

120. *Id.*

121. *Id.* at 686.

122. *Id.* (citing Note, *Developments in the Law—Equal Protection*, *supra* note 116, at 1173-74).

123. *Id.* at 687.

124. Daniel J. Kevles & Leroy Hood, *The Deoxyribonucleic Acid Test*, S.F. CHRONICLE, Dec. 6, 1992, (This World), at 8. For example, on or around 1970, fear spread that individuals with sickle-cell trait—those who possess a recessive gene for the disease—might suffer damage to red blood cells in the reduced oxygen of high altitudes. The Air Force Academy, therefore, implemented a policy prohibiting such individuals (the overwhelming majority of whom were black) from enrolling. Furthermore, several major commercial air carriers restricted such individuals to ground duty; these individuals were also charged higher insurance premiums. The fact that these individuals were permanently asymptomatic heterozygotes (carriers) for the recessive sickle-cell genetic condition identifies this group as a class bearing such incidents of genetic difference which although always present

clusion that suspect status is appropriate for those individuals who possess a genetic abnormality that does not inhibit those individuals' functionality. First, a genetic defect is clearly immutable to the extent that no technology currently exists that can change the makeup of any individual possessing that trait. Thus, as with sex, which is itself a genetically determined characteristic, genetic markers identifying an individual as at risk for or as a carrier of cystic fibrosis, muscular dystrophy, or Huntington's chorea define a suspect class.

The next crucial question posed by Justice Brennan's analysis is the extent to which such a genetic marker inhibits current function. To the extent an individual falls into a category which identifies him for discrimination—*i.e.*, those individuals who are asymptomatic but carry a gene(s) that increases the probability that they will develop some disease, individuals who are, heterozygotes (carriers) for some recessive or X-linked genetic condition but who are and will remain asymptomatic, individuals who have one or more genetic polymorphisms that are not known to cause any medical condition, and immediate relatives of individuals with known or presumed genetic conditions—such individuals, by definition, have no current dysfunction that relates to "ability to perform or contribute to society."[125] Thus, under the test proposed in *Frontiero*, any state action implicating such a genetic trait would be subject to strict scrutiny and most probably struck down.

B. Stigma As a Basis For Heightened Judicial Scrutiny

The Supreme Court has also examined the extent to which stigma either alone or in conjunction with an immutable characteristic should be a basis for identifying a suspect class and applying concomitant strict scrutiny to regulations or legislation which reflect such a stigma.[126] The Court stated that "any statute must be stricken that stigmatizes any group or that singles out those least well represented in the political process"

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in the genetic material of those individuals, the trait bears no relationship to their functionality as members of society. *Id.* at 10.

125. *Frontiero*, 411 U.S. at 686.

126. Wygant v. Jackson Bd. of Educ., 476 U.S. 267, 285 (1986) (O'Connor, J., concurring) (quoting University of Cal. Regents v. Bakke, 438 U.S. 265, 361-62 (1978) (opinion of Brennan, White, Marshall & Blackmun, JJ.)); Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. 432, 466 (1985) (opinion of Marshall, J.); Plyler v. Doe, 457 U.S. 202, 223 (1982); *id.* at 238-39 (Powell, J., concurring); University of Cal. Regents v. Bakke, 438 U.S. 265, 361-62 (1978) (opinion of Brennan, White, Marshall & Blackmun, JJ.); Kahn v. Shevin, 416 U.S. 351, 357 (1974) (Brennan, J., dissenting); San Antonio Indep. Sch. Dist. v. Rodriguez, 411 U.S. 1, 121-22 (1973) (Marshall, J., dissenting).

and held that the appropriate standard of review is "not 'strict' in theory and fatal in fact, because it is stigma that causes fatality—but strict and searching nonetheless."[127] Thus, in addition to ascertaining the extent to which a particular characteristic is immutable, the Court has taken into consideration the extent to which a characteristic results in some stigma or burden imposed upon the group defined by that characteristic.[128]

V. Privacy And Scarlet Letters Of Genetic Dissimilarity

The genetic marker, a common characteristic from which an individual cannot escape, necessitates strict judicial scrutiny not only because it is immutable but because it results in social stigma. Again the genetic material of an individual, to the extent it is public information, results in a figurative scarlet letter signifying genetic dissimilarity or variation and ensures discriminatory treatment. Although equal protection theory and resulting antidiscrimination measures provide methods of alleviating the stigma associated with public disclosure of genetic information, another option for protecting individuals with genetic abnormalities lies in limiting the disclosure of such information from the outset. Constitutional and legal support for such a policy may be derived from the individual's fundamental right to privacy.

A. Judicially Derived Privacy Interests

The public dissemination of genetic information and resulting stigma attached thereto implicate another constitutional interest, the individual's stake in maintaining the privacy of such information. Conceivably, discrimination could be avoided if no information were available upon which distinctions could be made between those individuals with "normal" genotypes and those with abnormal genetic characteristics. In contrast to equal protection, this area has been more fully charted by commentators.[129] Unfortunately, there appears to be little protection in

127. University of Cal. Regents v. Bakke, 438 U.S. 265, 361-62 (1978) (opinion of Brennan, White, Marshall & Blackmun, JJ.).

128. At least one commentator has suggested that these two factors essentially recast the test set forth in footnote four of *United States v. Carolene Products Co.*, equating footnote four's insistence on discreetness and insularity to a correspondent insistence on, "immutability—on the power of observers unambiguously to associate individuals with the minority, on the inability of individuals to drift out of the minority to which they are assigned." Janet E. Haley, *The Politics of the Closet: Towards Equal Protection for Gay, Lesbian, and Bisexual Identity*, 36 UCLA L. Rev. 915, 931 (1989).

129. *See* Nobles, *supra* note 2, at 2097; Fletcher & Wertz, *supra* note 75, at 758, 763, 787-88; Nicholas A. Ashford et al., Monitoring the Worker for Exposure and

the area of employment or insurance apart from theoretical constitutional restraints upon public employers, and scattered state constitutional[130] and statutory privacy provisions.[131] The federal constitutional restraints, however, reveal several bases upon which courts might discern a fundamental privacy interest applicable to the genetic material of a particular individual. They also provide support for legislative measures to protect the privacy of genetic material.

Privacy has been identified in a number of Supreme Court cases as a fundamental value of the provisions of the Bill of Rights.[132] However, it was not until *Griswold v. Connecticut*[133] that the Court derived an independent right to privacy from the confluence of several provisions of the Bill of Rights.[134] This "penumbral" zone of privacy has been held to include a woman's right to terminate a pregnancy,[135] but has not ex-

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DISEASE: SCIENTIFIC, LEGAL, AND ETHICAL CONSIDERATIONS IN THE USE OF BIOMARKERS 125-39 (1990); OFFICE OF TECHNOLOGY ASSESSMENT, BIOLOGY, MEDICINE, AND THE BILL OF RIGHTS—SPECIAL REPORT 15 (1988); L. ANDREWS, THE FUTURE OF CONFIDENTIALITY OF GENETIC INFORMATION, *in* MEDICAL GENETICS: A LEGAL FRONTIER 209 (1987).

130. Council on Ethical Judicial Affairs, *supra* note 19, at 2094. This particular author noted that state constitutional provisions protecting the right of privacy are found in Alaska, Arizona, California, Florida, Hawaii, Illinois, Louisiana, Montana, South Carolina, and Washington. California, in particular, prohibits reasonable searches and seizures by private and public employers. CAL. CONST. art I, § 13 (West 1982).

131. Nobles, *supra* note 2, at 2094 (citing CAL. CIV. CODE §§ 56-56.37 (West 1982); MONT. CODE ANN. §§ 50-16-302 - 50-16-314 (1984); R.I. GEN. LAWS §§ 5-37.3-1 - 5-37.3-10 (1956 & Supp. 1982)).

132. Loving v. Virginia, 388 U.S. 1, 12 (1967) (marriage); Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (contraception); Skinner v. Oklahoma, 316 U.S. 535, 541-42 (1942) (procreation); Pierce v. Society of Sisters, 268 U.S. 510, 535 (1925) (child rearing and education).

133. 381 U.S. 479 (1964).

134. *Id.* The Court, in an opinion by Justice Douglas, stated:

> The foregoing cases suggest that specific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance. Various guarantees create zones of privacy. The right of association contained in the penumbra of the First Amendment is one, as we have seen. The Third Amendment in its prohibition against the quartering of soldiers "in any house" in time of peace without the consent of the owner is another facet of that privacy. The Fourth Amendment explicitly affirms the "right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures." The Fifth Amendment in its Self-Incrimination Clause enables the citizen to create a zone of privacy which government may not force him to surrender to his detriment. The Ninth Amendment provides: "The enumeration in the Constitution, of certain rights, shall not be construed to deny or disparage others retained by the people."

Id. at 484.

135. Roe v. Wade, 410 U.S. 113, 153 (1973). *See* George P. Smith, II & Roberto Iraola,

tended protection to private consensual sodomy,[136] a depositor's interest in not disclosing bank records,[137] or a taxpayer's interest in not disclosing tax records.[138] Nor has a privacy right been recognized for the otherwise proper acquisition and use of non-testimonial evidence.[139]

The Supreme Court, however, has recognized a privacy interest in a case analogous to the problem of disclosure of genetic information. In *Whalen v. Roe*,[140] the Court scrutinized a New York State statute which required that the State record in a centralized computer file the names and addresses of all persons who had obtained, pursuant to a doctor's prescription, drugs for which there were both lawful and unlawful markets.[141] The statutory scheme was attacked as an invasion of an individual's privacy interest against disclosure of personal matters.[142] The Court recognized this interest as falling within the "zone of privacy" but, because of the extensive security measures protecting the identity of patients from disclosure, the Court concluded that the New York program did not pose a sufficiently "grievous" threat to establish a constitutional violation.[143]

The Court in *Whalen* did not explicitly articulate the standard of review applied to the New York statute in its analysis. However, the extensive analysis of the statutory provisions for maintaining patient confidentiality suggests that the Court strictly scrutinized the statutory framework in light of the important privacy interests at issue.[144] Indeed, the Court went so far as to include in the record the independent investigation of similar California and Illinois reporting systems, both of which failed to reveal a single case of invasion of a patient's privacy.[145] Although not totally clear, the Supreme Court's holding in *Whalen* confirms the weight accorded to an individual's constitutional interest in not disclosing per-

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Sexuality, Privacy and the New Biology, 67 MARQ. L. REV. 263 (1984). *See generally* George P. Smith, II, *Limitations on Reproductive Autonomy for the Mentally Handicapped*, 4 J. CONTEMP. HEALTH L. & POL'Y 71 (1988).

136. Bowers v. Hardwick, 478 U.S. 186, 190-91 (1986).

137. United States v. Miller, 425 U.S. 435 (1976).

138. Fisher v. United States, 425 U.S. 391 (1976).

139. *Id.* at 399.

140. 429 U.S. 589 (1977).

141. *Id.* at 591.

142. *Id.* at 598-99. The Court also recognized the interest of the individual in the independent making of important decisions, such as the decision to receive medication without the threat of being labeled a drug addict. *Id.* at 599-600.

143. *Id.* at 600.

144. *Id.* at 600-03.

145. *Id.* at 601 n.27.

sonal information and the concomitant importance of protecting such an individual from the stigma of public scrutiny and reputational damage.

B. Fourth Amendment Interests

The Fourth Amendment to the United States Constitution provides that: "[t]he right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures, shall not be violated . . . ."[146] The Amendment guarantees the privacy of persons against invasive acts by officers of the government[147] or private parties acting as an instrument or agent of the government.[148] Where the government or its agent seeks to obtain physical evidence from a person, the Fourth Amendment privacy rights may be implicated in varying degrees.[149] Also, the Supreme Court has long recognized that physical intrusion which penetrates beneath the skin for the purpose of drawing blood for chemical analysis constitutes a Fourth Amendment search.[150]

In *Skinner v. Railway Labor Executives' Ass'n*,[151] the United States Supreme Court concluded that Fourth Amendment concerns were implicated by a drug and alcohol testing program prescribed by Federal Railway Administration regulations.[152] In reaching this conclusion, the Court noted that, like blood-testing, chemical analysis of urine reveals many private medical facts about an employee including such conditions as pregnancy, epilepsy, and diabetes.[153] Having recognized the existence of a Fourth Amendment interest, the Court proceeded to determine whether, in light of the government's interest in implementing such a drug testing program, the search was reasonable and thus constitutionally permissi-

146. U.S. CONST. amend. IV.

147. Skinner v. Labor Executives' Ass'n, 489 U.S. 602, 613-14; Camara v. Municipal Court of S.F., 387 U.S. 523, 528 (1967).

148. *Skinner*, 489 U.S. at 614; United States v. Jacobsen, 466 U.S. 109, 113-14 (1984); Coolidge v. New Hampshire, 403 U.S. 443, 487 (1971).

149. For example, initial detention of the person for the purpose of gathering evidence, may constitute a violation if the detention amounts to a meaningful interference with freedom of movement. INS v. Delgado, 466 U.S. 210, 215 (1984); *Jacobsen*, 466 U.S. at 113-14; Cupp v. Murphy, 412 U.S. 291, 294-95 (1973); Davis v. Mississippi, 394 U.S. 721, 726-27 (1969).

150. *Skinner*, 489 U.S. at 616; Schmerber v. California, 384 U.S. 757, 767-68 (1966).

151. 489 U.S. 602 (1989).

152. *Id.* at 618-19.

153. *Id.* at 617. The Supreme Court also agreed with the observation of the United States Court of Appeals for the Fifth Circuit that "few activities in our society are more personal or private than the passing of urine." *Id.* (quoting National Treasury Employees Union v. Von Raab, 816 F.2d 170, 175 (5th Cir. 1987)).

ble.[154] In its determination of the reasonableness of the search, the Court noted that although in most instances such a search must be accompanied by a judicial warrant issued upon probable cause,[155] the case fell within the recognized "special needs" exception making the warrant and probable cause requirement impracticable.[156] Thus, the Court proceeded to balance the governmental and privacy interests to determine the reasonableness of such a policy in light of all of the circumstances surrounding the search or seizure.[157]

This result has great significance when considering the prospect of a constitutional challenge to any genetic testing program, whether administered by the government or a private party acting at its behest. Although *Skinner* recognizes a Fourth Amendment privacy interest, it also indicates the willingness of the Court to accord, through a balancing process, little weight to the fundamental privacy right in comparison to the government's interest in obtaining and retaining information from any procedure, whether it be a blood test, urinalysis, or DNA fingerprint.[158]

There is, however, a basis for distinguishing a DNA test from these other procedures that may accord testing greater future protections. Namely, DNA mapping reveals characteristics inherent to the individual from whom the sample is drawn. Unlike a test for drugs or alcohol, which represents the concentrations of these substances at only one point in time, any variation from the normal genotype revealed by a DNA test represents a characteristic that is immutable during the lifetime of the individual. Arguably, the individual's privacy interest in such an immutable characteristic should be accorded greater weight for it provides a means of placing that individual in a discrete class. Nevertheless, in light

154. *Id.* at 619.

155. *Id.* (citing Payton v. New York, 445 U.S. 573, 586 (1980)).

156. *Id.* (citing Griffin v. Wisconsin, 483 U.S. 868, 873 (1987)).

157. *Id.*

158. The Court, in a decision issued on the same day, incorporated by reference the analytical framework articulated in *Skinner* and reached the same result on the facts presented in *Treasury Employees v. Von Raab*, 489 U.S. at 656. The balancing of the relative interests of the government and those privacy interests asserted by the treasury employees seeking relief from a similar drug testing regulation lead to the same result as *Skinner*. *See also* Kobrin, *supra* note 113, at 1293.

Interestingly, a recent Office of Technology Assessment survey of 500 U.S. companies found only one percent had policies on genetic testing of applicants or employees. Sixty percent of the company health offices said the decision to perform such tests should be the employer's. David Brown, *Individual Genetic Privacy Seen as Threatened*, WASH. POST, Oct. 20, 1991, at A6. *See also* Mark A. Rothstein, *Discrimination Based on Genetic Information*, 33 JURIMETRICS J. 13 (1992).

of the Court's increasing willingness to sacrifice privacy rights asserted under the Fourth Amendment in favor of government policy,[159] it appears unlikely that the Fourth Amendment alone can effectively serve as the basis for a successful constitutional challenge to DNA testing.

VI. THE HUMAN GENOME PRIVACY ACT: A MODEL LEGISLATIVE SOLUTION?

In the area of privacy, there has been only one federal legislative proposal which, as a model statute, merits study. The Human Genome Privacy Act (HGPA) was introduced before the House of Representatives by Representative Conyers on September 13, 1990.[160] Although no action was taken on the bill following its introduction, its language responds in many respects to the problems of confidentiality of genetic information in the workplace and it may be fully expected that similar legislation will be proposed over time.[161] The purpose of the bill was to safeguard individual privacy of genetic information by proscribing the misuse of records maintained by agencies or their contractors or grantees for the purposes of research, diagnosis, treatment, or identification of genetic disorders.[162]

159. *See Skinner*, 489 U.S. at 602; *Von Raab*, 489 U.S. at 656.

160. H.R. 5612, 101st Cong., 2d Sess. (1990). This legislation is no longer pending. In October, 1992, Congress adjourned *sine di*. Thus, all unpassed bills pending at that time died. This HGPA or similar legislation, has not been reintroduced.

Internationally, it has been suggested that either a moratorium be imposed on the collection and use of genetic information until the Council of Europe can draft an appropriate Bioethics Convention dealing with the area or—alternatively—an expanded interpretation of Articles 2 and 26 of the International Convention on Civil and Political Rights can be sought. These two articles prohibit discrimination on the grounds of race, sex, or religion. Sjef Gevers, *Use of Genetic Data, Employment and Insurance: An International Perspective*, 7 BIOETHICS 126 (1993).

After two years of study, the Committee on Bioethics of the Council of Europe has recently produced a draft convention on Bioethics and referred it to the European governments for consultation. Tony Sheldon, *European Experts Produce Draft on Bioethics*, 309 BR. MED. J. 221 (July 23, 1994). *See generally* YVONNE M. CRIPPS, CONTROLLING TECHNOLOGY: GENETICS, ETHICS & THE LAW, ch. 5 (1980).

161. Lori B. Andrews & Ami S. Jaeger, *Confidentiality of Genetic Information in the Workplace*, 17 AM. J.L. & MED. 75, 108 (1991). The authors identify a need for new policies protecting the confidentiality of genetic information and suggest the drafting of a model law. The model statute advocated in the article would mandate that job applicants and employees be informed if they will be subject to genetic screening or genetic monitoring. Furthermore, the results of such testing would be available to the employee on request. Disclosure to employers would be limited to information about the individual's fitness to perform a particular job. Finally, disclosure to third parties would be prohibited without employee consent. *Id.*

162. H.R. 5612, 101st Cong., 2d Sess.

The bill would have provided to individuals access to records concerning their genome as maintained for any purpose by agencies of the federal government.[163] The language of the proposed legislation may be studied as a potential model for future legislation. The bill is divided into five sections. Part A sets forth the definitions for purposes of the Act. It broadly defines "genetic information" as "any information that identifies all or any part of a genome identifiable to a specific individual."[164]

Part B, entitled "Inspection of Genetic Information," requires a government agency[165] to permit an individual to inspect and have a copy of any genetic information the agency maintains about the individual.[166] It further sets forth procedures for correcting or supplementing genetic information held by an agency.[167] Section 114 of the Act,[168] entitled "Disclosure of Genetic Information," proscribes the unauthorized[169] disclosure of genetic information about an individual other than to the individual or the individual's designated representative. Section 116 of the Act requires an agency that provides by contract or grant for the maintenance, development, analysis, or identification of genetic information, to apply the Act to such information, thus making the Act and re-

163. *Id.*

164. *Id.* § 101(2).

165. "Agency" is defined in Part A as "any executive department, military department, Government corporation, Government controlled corporation, Government contractors, or Government grantees maintaining genetic information pursuant to Federal contracts and/or, grants or other establishment in the executive branch of the Government (including the Executive Office of the President), or any independent regulatory agency." *Id.* § 101(1).

166. *Id.* § 111(a)(1).

167. *Id.* § 112(a).

168. *Id.* § 114.

169. The predicate for proper authorization is set forth in detail in section 115 of the Act. This section requires that an individual has authorized disclosure to a person of genetic information maintained by the agency only if:

> (1) the authorization is (A) in writing, (B) dated, and (C) signed by the individual;
>
> (2) the agency is specifically named or generically described in the authorization as authorized to disclose such information;
>
> (3) the person to whom the information is to be disclosed is specifically or generically described in the authorization as the person to whom such information may be disclosed;
>
> (4) the information to be disclosed is described in the authorization;
>
> (5) the purpose of the disclosure is specified in the authorization; and
>
> (6) the disclosure occurs before the date of the event (if any), specified in the authorization, upon which the authorization expires.

Id.

sulting regulations applicable to government contractors or grantees.[170]

Part C of the Act delineates exceptions to the above described nondisclosure rule, allowing unauthorized disclosures: (1) within an agency for official use;[171] (2) to a medical professional for use in connection with care or treatment of the individual;[172] (3) for specified health and safety reasons;[173] and (4) as directed by a court.[174] Part D further allows unauthorized disclosure to a law enforcement agency for identification or location of a suspect or fugitive.[175] It also sets forth access procedures for law enforcement summonses, subpoenas, warrants, and search warrants[176] and provides for challenge procedures to law enforcement summonses and subpoenas.[177]

Part E of the Act, entitled "Enforcement," establishes criminal penalties for requesting or obtaining genetic information or authorization from an individual through false pretenses or theft.[178] It further provides for civil relief by any individual whose rights have been knowingly or negligently violated,[179] and criminal penalties for the knowing improper disclosure of information as well as for the failure to comply with the notice requirements of the Act.[180]

The most illuminating part of this legislation is set forth in the findings and purposes section. Section 2 provides in pertinent part:

> Sec. 2. (a) The Congress finds that -
> (1) the right to privacy is a personal and basic right protected by the Constitution of the United States;
> (2) the collection, maintenance, use, and dissemination of genetic information can threaten an individual's right to privacy;
> (3) the increasing use of biotechnology and sophisticated genetic screening techniques in the advancement of the Human Genome Project and the expanded understanding of the genetic links to a variety of physical and psychological diseases and dis-

170. *Id.* § 116.
171. *Id.* § 122.
172. *Id.* § 123.
173. *Id.* § 124.
174. *Id.* § 125.
175. *Id.* § 131(a)(1).
176. *Id.* § 132. This section adopts the constitutionally protected requirement of reasonable grounds and probable cause in instances where a law enforcement authority wishes to gain unauthorized access to genetic records from an agency. *Id.* § 132(b)(1).
177. *Id.* § 133.
178. *Id.* § 141(a).
179. *Id.* § 142(a).
180. *Id.* § 143(a).

> orders have greatly magnified the potential harm to individual privacy that can occur from any collection, maintenance, use, or dissemination of personal genetic information;
> (4) the opportunities for an individual to secure education, employment, health care, insurance, and credit, and his or her right to due process and other legal protections are endangered by the misuse of genetic information systems;
> (5) in order to protect the genetic privacy of individuals in informational systems maintained by agencies, it is necessary and proper for the Congress to regulate the collection, maintenance, use and dissemination of information by such agencies.[181]

The recognition in sections 1 and 2 of a fundamental privacy right regarding an individual's genetic material is crucial to extending protection to those individuals with abnormal genotypes.[182] Section 3 recognizes the increasing threat to privacy interests occasioned by the use of genetic screening as well as the further advancement of the Human Genome Project.[183] Finally, section 4 specifies those areas of education, employment, health care, insurance, and credit in which, pursuant to section 5, Congress has an interest in protecting the rights of genetically "abnormal" persons.[184]

However worthy the statement of policy set forth in the above section, the question nevertheless arises as to whether language such as that advocated in the HGPA is the most effective means to reach this end.[185] For example, although section (2)(a)(4) of the HGPA specifies "due process" as one of the constitutionally protected rights that should be accorded to the genetically dissimilar, it is not clear whether equal protection as a basis for non-discrimination is included in due process.[186] The actual

181. *Id.* § 2(a).
182. *Id.* § 2(a)(1), (2).
183. *Id.* § 2(a)(3).
184. *Id.* § 2(a)(4), (5).
185. At least one commentator has questioned its potential efficacy and concluded that although well intentioned and timely, the Act's effectiveness is doubtful. Nobles, *supra* note 2, at 2119. It was observed first that its operative language is vague and, furthermore, that many of the requirements imposed on federal agencies by the act are already in force. Finally, the objectives, if not the language of the HGPA, are already reflected in the current versions of the Privacy Act as well as various state statutes. *Id.* (citing Privacy Act of 1974, 5 U.S.C. § 552a (1988)). It has been proposed that the policy objective of the HGPA be implemented by amendment to preexisting laws such as the Privacy Act, the Americans with Disabilities Act and the Rehabilitation Act. *Id.* at 2119-20 (citing Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12011-12213 (1990); The Rehabilitation Act of 1973, 29 U.S.C. §§ 701-794 (1988)).
186. H.R. 5612, § 2(a)(4).

terms of the legislation do not define discrimination or articulate protections or relief from discrimination. Thus, although the protection of due process rights appears to be one of the main goals of the legislation, such protection is cast exclusively in terms of privacy. In relying exclusively on privacy, the HGPA has left unused one of the principal constitutional implements by which the rights of individuals with abnormal genotypes might be protected.

Furthermore, it appears from a policy perspective that the HGPA overlaps with two important federal statutes. In lieu of enacting new law, Congress could easily amend either the Americans with Disabilities Act (ADA)[187] or the Federal Privacy Act[188] to include relevant provisions of

187. 42 U.S.C. §§ 12101-12213. The ADA prevents employers from discriminating against individuals who have or have had a history of a disability that involves a mental or physical impairment that limits a major life activity. *See* Charles B. Gurd, *Whether a Genetic Defect Is a Disability Under the Americans With Disabilities Act: Preventing Genetic Discrimination by Employers*, 1 ANNALS HEALTH L. 107, 118 (1992). Section 102(a) of the ADA, 42 U.S.C. § 12112(a) states:

> No covered entity [employer, employment agency, labor organization or joint labor-management committee excluding the federal government] shall discriminate against a qualified individual with a disability because of the disability of such individual in regard to job application procedures, the hiring, advancement, or discharge of employees, employee compensation, job training, and other terms, conditions and privileges of employment.

42 U.S.C. § 12112.

Section 102(c)(2) of the ADA, 42 U.S.C. § 12112(c)(4)(A), continues by prohibiting pre-employment medical examinations. Accordingly, no pre-employment questionnaires may be used by prospective employers nor may they inquire of potential employees whether they have any medical conditions such as epilepsy, diabetes, or hypertension. Only questions that focus on specific, job related functions may be asked of applicants. 42 U.S.C. § 12112(c)(4)(B). This statutory prohibition against pre-employment medical examinations will assist greatly in curing abuses in discriminatory hiring that would otherwise be based on genetic testing.

Regarding disabilities under the ADA, the current policy is "can't ask, don't tell." The major uncertainty with this policy is whether a genetic trait that has not manifested itself counts as a disability within the meaning of the statute. Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New Technology*, 74 B.U. L. REV. 1, 13-18 (1994).

188. Privacy Act of 1974, 5 U.S.C. § 552a (1988). The Privacy Act restricts the type of information that the federal government may collect. Thus, it provides that the government may retain only the minimal amount of records possible. The statute provides: "(e) Agency requirements.—Each agency that maintains a system of records shall—(1) maintain in its records only such information about an individual as is relevant and necessary to accomplish a purpose of the agency required to be accomplished by statute or by executive order of the President." 5 U.S.C. § 552a(e)(1). Furthermore, subject to certain exceptions, the Act provides for protections from disclosure:

> (b) Conditions of disclosure.—No agency shall disclose any record which is contained in a system of records by any means of communication to any person, or to

the HGPA. Although addressing analogous discrimination and privacy issues, the ADA and the Privacy Act fall short of extending explicit protection to asymptomatic individuals with abnormal genotypes.[189] Thus, it appears that the most fruitful path in the legislative arena would be by amendment to these legislative schemes. These statutes, as amended, should recognize the fundamental importance of privacy and equality rights while explicitly extending the protection of these principles to problems of discrimination based on genetic information. Such amendments to an established statutory framework would simplify the process of effectuating newly enacted protections, rather than establishing a new area of law subject to the promulgation of regulations and judicial clarification.

VII. CONCLUSIONS

Advances in rDNA technology and screening techniques have created

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another agency, except pursuant to a written request by, or with the prior written consent of, the individual to whom the record pertains.

5 U.S.C. § 552a(b). This legislation, however, only serves as a protection against disclosure by the federal government.

189. *See* Gurd, *supra* note 187, at 118. Because of the statutory requirement of some past or present disfunction, many individuals who have a genetic defect are not covered. Furthermore, the ADA is inapplicable to carriers or individuals receiving treatment to prevent gene expression. Accordingly, the ADA provides no protection from discrimination based on an individual's genetic profile. *See also* Larry Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 110, 123 (1991) (explaining that a genetic condition which does not cause substantial impairment may not constitute a disability as defined under the ADA). The agency charged with enforcing the ADA, the Equal Employment Opportunity Commission, has determined that there is no individual coverage under the law until one is determined to be symptomatic. Thus, presymptomatic individuals with late or onset disorders, as for example adult polycystic kidney disease, would have no coverage under the Act. Similarly, those carriers of recessive disorders such as cystic fibrosis are also not covered and could be denied employment. Neil A. Holtzman & Mark A. Rothstein, *Invited Editorial: Eugenics and Genetic Discrimination*, 50 AM. J. HUM. GENETICS 457, 458 (1992). *See also* Eric T. Juengst, *Priorities in Professional Ethics and Social Policy for Human Genetics*, 266 JAMA 1835 (1991).

What can be seen in the disability rights movement is a direct ideological challenge to medical genetics or genetic determinism. It has been urged that rather than prevent the birth of persons with significant disabilities (e.g., blindness), society should change the ways in which it views these individuals and thus accept them as equals. COOK-DEEGAN, *supra* note 71, at 252.

With respect to the Privacy Act, the main defect is that it restricts only the types of information that may be collected by the federal government. However, its provisions seem to apply broadly, and would thus include genetic information with other types of personal data. *See* Andrews & Jaeger, *supra* note 161, at 101.

a new genus in the taxonomy of genetic information that is particularly susceptible to misuse both by state and private entities. As with any new invention—whether a genetically altered plant or a laboratory technique for identifying mental illness—such technical capability and resulting information is often met with fear.[190] Similarly, those individuals identified by such technology as genetically distinct from the social norm are at risk for disparate and intrusive treatment.[191]

The perception by both public and private institutions that identifying and singling out persons with genetic abnormalities serve either public or private commercial interest in turn sets the stage for an erosion of fundamental privacy rights based on such genetic information. Whatever the risks from the perspective of individual rights, however, it is increasingly clear that rDNA techniques and the valuable knowledge they generate provide great hope for alleviating human suffering both as diagnostic measures to avoid genetically related illness and as therapeutic techniques to cure such illness.[192] Discerning a rational course between the often conflicting interests of individual rights and the greater social good in the application of rDNA technology presents particularly difficult problems regarding how to apply existing constitutional precedent and public policy to this new technology. Indeed, the factual permutations raised by the use of rDNA and screening techniques appear at first consideration novel and strange.

Closer examination, however, reveals recurring constitutional and policy questions. For example, to the extent such genetic markers are immutable characteristics which subject a class of individuals to any stigma, the Equal Protection Clause of the Fourteenth Amendment arguably recognizes the need for heightened judicial scrutiny of government action affecting such a suspect class.[193] Exacting judicial scrutiny imposes on the state and its agents a higher standard of rationality. As with any suspect class like race or alienage, such scrutiny attempts to discern the extent to

190. In light of the attempts by the eugenics movement to wield limited technology this fear is perhaps not unreasonable. *See supra* note 9 and accompanying text. *See also* DANIEL J. KEVLES, IN THE NAME OF EUGENICS Ch. XIII (1985).

191. *See supra* note 10 and accompanying text.

192. *See supra* note 3 and accompanying text. *See also* Rick Weiss, *Genetic Counseling's New Challenge*, WASH. POST, Jan. 4, 1994, (Health Magazine), at 10; Owen D. Jones, *Reproductive Autonomy and Evolutionary Biology: A Regulatory Framework for Trait-Selection Technologies*, 19 AM. J.L. & MED. 187 (1993).

193. Plyler v. Doe, 457 U.S. 202, 216-17 (1982). *See also supra* note 101 and accompanying text.

which fear or prejudice may have supplanted rational discourse in the making of public policy.

Similarly, fundamental privacy rights recognize an individual's interest in not disclosing personal information that might hold him or her up to unnecessary public scrutiny and reputational damage.[194] This principle applies with particular force to an individual's interest in concealing from public scrutiny the makeup of his or her genetic map.[195] Although these rights, especially as defined by the Fourth Amendment, are qualified when balancing society's interest in obtaining and using genetic information courts and legislatures should give great weight to the private nature of such information given its personalized and sensitive nature.

Finally, in the legislative sphere, the logical complement to recognizing rights of equal protection and privacy for individuals with genetic abnormalities is the extension of those rights as protections not only against state action but also against private entities. Amendments to both the ADA[196] and the Federal Privacy Act[197] would effectuate the stated purpose of the Human Genome Privacy Act,[198] while avoiding its vagueness and technical flaws. More important, such legislation would further advance the principle that absent some compelling reason, private individuals and institutions will be charged with treating individuals, whose genetic maps diverge from the norm, as they would a person with a completely normal genotype.

Quite obviously, the wide number of social dislocations produced by the biotechnological advances of the New Biology neither must nor should be a serious matter of constitutional concern.[199] Rather, efforts should be undertaken with resolve to sharpen ethical constructs for principled decision making within the professional bodies concerned with the development and management of the New Biology. The state legislatures and courts should—in partnership with medical scientists, ethicists, philosophers, and the other architects of the new biological sciences—endeavor to regulate, and thereby resolve, the complexities of these

194. *See supra* notes 135-36 and accompanying text.

195. *See generally* Kobrin, *supra* note 113.

196. 42 U.S.C. §§ 12101-12213. *See generally* Lawrence O. Gostin, *The Americans with Disabilities Act and The Corpus of Anti-Discrimination Law: A Force for Change in the Future of Public Health Regulation*, 3 HEALTH MATRIX: J.L. MED. 89 (1993) (discussing the ADA).

197. 5 U.S.C. § 552a.

198. H.R. 5612, 101st Cong., 2d Sess.

199. Sheila Jasanoff, *Biology and The Bill of Rights: Can Science Reframe the Constitution?*, 13 AM. J.L. & MED. 249, 288 (1987).

biotechnological sciences.[200]

To be sure, the constitutional challenges raised as a direct consequence of the startling advances in bio-science are unique, for they hold every promise of changing some of the most fundamental principles of this country's political order—challenges "that the individual human being is autonomous and exercises free will, that all people are entitled to equal treatment, that individuals enjoy a legitimate expectation of privacy in their dealings with the state and that freedom of scientific inquiry and expression can flourish along with freedom of religion."[201]

While the Human Genome Initiative will provide startling genetic maps, it remains for the law to sequence or identify the policy issues inherent in the complex issues of medical genetics and then to proceed to map them or, in other words, determine them and then resolve them to the extent possible within legal doctrines.[202] This, in turn, forces a need to examine critically the true social significance of the concepts of normality and abnormality.[203] With this all comes a fear—rational or irrational—that laws will be passed requiring everyone to submit to gene therapy or even, as the case may warrant, "provide personally identifiable genetic material for purely scientific uses."[204] Yet, interestingly, individuals are less likely to be interested in knowing about their genetic profiles if they are obsessed with an overriding fear that such knowledge will then be used to punish them. Society thus will be forced to develop both ethical and legal norms designed to protect those members of society at higher risk from genetic discrimination.[205]

From a more positive side, universal access to the wide opportunities of genetic services will allow persons "to act on the perception that it is good to want to know about genetic risks."[206] Accordingly, when the benefits of genetic diagnosis and treatment become more evident over time, genetic information will, in turn, become far less threatening and

200. *Id.*

201. *Id.* at 287. See George P. Smith, II, *Intrusions of a Parvenu: Science, Religion and the New Biology*, 3 PACE L. REV. 63 (1982).

202. Lori B. Andrews, *Genetics and the Law*, Introduction, 39 EMORY L.J. 619, 620 (1990).

203. Alexander M. Capron, *Which Ills to Bear?: Reevaluating the "Threat" of Modern Genetics*, 39 EMORY L.J. 665, 694 (1990). *See* Rick Weiss, *Getting New Genes*, WASH. POST, Feb. 15, 1994, (Health Magazine), at 11.

204. *See* Capron, *supra* note 203, at 695. *See generally* Sidney A. Shapiro, *Biotechnology and The Design of Regulation*, 17 ECOLOGY L.Q. 1 (1990).

205. Fletcher & Wertz, *supra* note 75, at 759. *See* COOK-DEEGAN, *supra* note 71, at ch. XVI.

206. *Id.*

stigmatizing.[207]

In order to meet these new challenges, law and sciences must march together as full partners and not—as in the past—with law behind the scientific cadence. All too often, as former Chief Justice Warren E. Burger observed, "[t]he law does not search out as do science and medicine; it reacts to social needs and demands."[208] It is thus vitally incumbent upon the law to develop a contemporary agenda for social change and changing socio-political needs instead of responding simply to or reacting to change itself—especially so here with the Age of The New Biology.[209] In the final analysis, then, it is well to recognize that: "Each new power won by man is a power *over* man as well."[210]

207. *Id.*

208. Warren E. Burger, Reflections on Law and Experimental Medicine, *reprinted in* 1 ETHICAL, LEGAL AND SOCIAL CHALLENGES TO A BRAVE NEW WORLD 211 (George P. Smith, II, ed., 1982).

209. *See* Michael J. Flower & Deborah Heath, *Micro-Anatomo Politics: Mapping The Human Genome Project*, 17 CULTURE, MED. AND PSYCHIATRY 27 (1993); George P. Smith, II, *Biomedicine and Biomedical Ethics: De Lege Latta, De Lege Ferenda*, 9 J. CONTEMP. HEALTH L. & POL'Y 233 (1993).

210. C.S. LEWIS, THE ABOLITION OF MAN 71 (1965).